

# The status of anencephalic babies: should their bodies be used as donor banks?

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## Author's abstract

*In recent months there has been considerable discussion on the ethics of using organs from anencephalic babies for transplantation purposes.*

*The heart of an anencephalic in Ireland was so used, but the recipient died very soon after the operation. Since this case came to light the Royal College of Physicians has imposed a ban on the use of these babies as donors while a working party investigates the issues involved. \**

*This article attempts to examine the problem and reaches the conclusion that in practice it is not ethical to use the organs of anencephalics for transplants.*

In considering this issue there are several very basic questions which need to be addressed before any decision can be reached. Principal among these are: a) what constitutes a living human being, b) what constitutes a 'person' to whom we ascribe rights, if different from a mere human being, c) what is our definition of death, and is the hastening of death acceptable if it will benefit someone else, and d) what rights do human beings or persons have, and how do the anencephalic fit into this system. I will not take these in strict order since they are all interconnected, but I believe these are the most important points to consider.

I take as my definition of 'human being' any successful fusion of egg and sperm. The World Health Organisation (WHO) definition of a livebirth as stated in article 23 of its constitution is 'the expulsion or extraction from its mother of a product of conception irrespective of the duration of the pregnancy which after such a separation breathes, or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscle whether or not the umbilical cord has been cut or the placenta is attached. Each product of such a birth is considered liveborn'. The legal definition of death in the UK is irreversible cessation of function of the brain stem (1). I take these two as defining the boundaries of life, and therefore consider

any human being existing between these two perimeters as living.

The differing concepts of 'personhood' as opposed to 'humanity' have been well documented, and on the basis of such differentiation rests our resolution of life and death issues such as abortion and the killing of newborn handicapped babies. It is only by regarding the unborn and newborn as beings with fewer rights, although undeniably both living and human, that we can justify terminating those lives, and this is particularly relevant in the case of anencephalics. Those who defend using their bodies as organ donor banks often justify that view by remarking that most are aborted anyway, presuming that abortion is legitimate either in this case alone, or in all cases. If it is legitimate in this or any case, it can only be so because the baby is ascribed fewer rights than those of us who are older.

There are several possible standpoints from which to decide whether one gains human rights when one begins to live, or when one begins to be a 'person', or indeed whether these two events are one and the same thing. The most important of these standpoints are perhaps the utilitarian, the Kantian and the pro-life. I believe we can only ethically base our treatment of specific cases on a sound general theory, which is why it is important to consider these possible theories in some detail.

If one takes a utilitarian approach, the weakest will inevitably lose out, since they are powerless and 'useless', in economic terms at least. Thus, since increasing the sum total of pleasure in the world is the main aim of utilitarianism, and since anencephalics are regarded as incapable of enjoying any kind of pleasure, they can only be 'good' for what they have to offer others – those considered more worthy of rights. This would allow anencephalics to be used as donor banks, whether living or dead (the distinction would be irrelevant here). It would also justify using me as a donor bank for someone more physically perfect (I am confined to a wheelchair due to spina bifida), and, depending on our view of relative worth, it would justify using any of us as a donor if someone of the

## Key words

Anencephaly; organ transplants.

\* See page 164 for a brief summary of the working party's report.

status of Einstein, or Beethoven, or even Bob Geldof, needed one of our organs to survive. The problem with this view is that as well as enabling us to use the bodies of the anencephalic, it could also justify slavery and ultimately the giving up of any commodity which might enhance a general, as opposed to an individual, good. This would make medicine very difficult to practise, since I doubt if many people would be willing to go to a doctor with views such as these.

The main problem with the Kantian view of rights and personhood as stated in the second formulation of the Categorical Imperative – that we should act so as to treat humanity always as an end and never as only a means – is that this would seem to demand a degree of rationality. Kant himself believed that we must treat entities morally only when they are rational (or potentially so) because our being able to do so is itself a rational judgement (2). Again this would allow anencephalics to be used as donors. But why is rationality so important? None of us are rational when we are asleep, neither can we be certain our rationality is in only temporary suspension then. What if we die before waking? What about mentally ill and mentally handicapped people, and animals? May we only *not* torture and kill them because of the effect that would have on us? If so, and non-rationality equals non-personhood equals no rights, why should we be any more concerned about treating such beings with respect than we are about respecting the rights of inanimate objects? Yet even those who would abort the mentally handicapped and use the bodies of anencephalics as donors still try to argue that they are treating them 'with respect'.

I believe the pro-life view, that rights accrue to all living human beings, and that that and 'personhood' are interchangeable terms is not only a humane but also a logically consistent philosophy. In my view there can be no sound differentiation between the two, and that being so, I believe individual rights begin when individual lives begin – at conception – and should be protected from then on.

Transplants from those other than anencephalics are subject to very strict rules, and the donor must have consented and/or be physically dead. I can see no reason why anencephalics should be treated any differently. They are not physically dead when used as donors, and are in any case incapable of consenting. I will consider later whether it is right for anyone else to consent on their behalf.

The anencephalics it is proposed to use are born alive within the WHO definition of livebirth. Although they are not capable of thinking they do have a brain stem which controls breathing, and certain reflex actions. This stem deteriorates after birth, and they die usually within a few hours, but by the time of natural death some organs, notably the heart, are useless for transplantation purposes. The heart needs to be taken at birth to be any use.

During the debate surrounding the use of the anencephalic baby in Cork, Ireland, for a heart

transplant, the duty administrator at Harefield Hospital, whose team performed the transplant, was quoted as saying 'The baby lived for a few hours and then died naturally. It was then attached to a mechanical ventilator while the heart was removed. The baby was not kept alive' (3). However, there could be no purpose in attaching the baby to a mechanical ventilator unless it had an active blood circulation to distribute the oxygen provided by that ventilator. Since doctors do not transplant hearts which are not beating, we must assume that the anencephalic's heart was beating while it was connected to the ventilator. Natural death in an anencephalic would be when the heart stopped beating, so in this case there was cardiac arrest followed by resuscitation. If this was sufficient for the doctors to pronounce the patient dead, would they also say that any other patient who has been resuscitated from cardiac arrest may also be used as an organ donor, without further criteria of death being met (3)? One would hope not.

To overcome the problem of using the organs of such babies it seems that moral gymnastics are being performed by some doctors and ethicists to persuade us that while physically alive, such babies are 'technically dead' and in fact in West Germany the concept that anencephalics have never been alive, despite the presence of a heart beat, has now been accepted by the courts.

It is not only there that such a trend is occurring. Ronald Cranford, Chairman of the Ethics and Humanities Committee of the American Academy of Neurology has said that 'they are not alive and they're not dead, but may have many of the characteristics of being dead. They have no consciousness' (1). By this definition of course, once again we enter a kind of inanimate limbo when asleep – not dead or alive. Dr Cranford could have said that anencephalics also have many of the characteristics, indeed some of the most important characteristics, of being alive, such as breathing and a beating heart, but he chose not to dwell on these.

A Department of Health and Social Security (DHSS) spokesman, commenting on this, said: 'This is a very delicate area. For kidney transplants there is no problem because the transplant can wait until the baby is brain dead. But in the case of heart transplants, which cannot wait, areas of the brain do develop and can control reflexes so that babies can react to pain for example. This is ethically a difficult area. It's a case of individual clinical judgement if the parents will allow it' (1). In other words they are *not* actually dead when the heart is taken, but because it is politic to consider them as such, we will treat them as if they were. Perhaps it's needless to say that I regard this as unequivocally wrong.

The anencephalic is an individual too, and it is the rights of the individual on which moral and ethical rules should be founded. If we want to preserve rights for ourselves against any onslaught from a more powerful aggressor, logical consistency, the primary

rule of all ethical thought, demands that we extend rights to those less powerful than ourselves in turn. If we say, on the other hand, that weak individuals may be sacrificed for the strong, and that the very severely handicapped may be killed to benefit the less severely handicapped, we once more embark down the particularly greasy, slippery slope of utilitarianism.

Sadly, anencephalics have few people to speak out in defence of their short lives. However, one person eminently qualified to comment said: 'As the father of an anencephalic boy I know that he could feel pain. He developed a clear personality, showing pleasure by smiling, displeasure by becoming agitated; he could even follow you round the room with his eyes. The only time he cried was when he was dying – a really pitiful heart-rending sound, which clearly showed his pain and distress. . . . I feel sick at the thought of babies like my son dying under the surgeon's scalpel' (4). Sir Raymond Hoffenburg confidently stated that 'there is no possibility of organs being taken from a patient who is still alive. This is an outmoded and idiosyncratic view held by a very small minority. We will not allow the need for organs, however urgent, to influence normal medical judgement of the condition of a living patient' (5). Unfortunately this is exactly what has happened in the case of anencephalics, and I do not think it is idiosyncratic to be worried about it. He went on to justify using them as living donors by saying that 'death is absolutely inevitable among babies born with anencephaly'. Unlike the rest of us, I suppose! I believe that each human life is of infinite value, and since infinity cannot be multiplied or divided, remaining always implicit in its infinity, so too is all human life precious and worthy of protection, no matter how long or short it may be.

It is perhaps not surprising that I should harbour a profound distrust of doctors, despite owing my life to them. Babies with my degree of defect are often aborted now, or sedated and starved to death after birth under the euphemism 'allowing' them to die. Dr James Appleyard, a paediatrician at Canterbury Hospital, said: 'We struggle for as long as possible to keep these small (anencephalic) babies alive' (6). But when we remember that some paediatricians starve babies to death because, like me, they would be unable to walk, I find it very hard to believe that they would treat more favourably those who are unable to think.

It is important here to remember that the law would have to be changed if anencephalics were to be legitimately used as living donors. It is only as such that they become useful as heart transplant donors, the technique for which, as we have seen, requires a beating heart. And a beating heart means that an anencephalic is alive. Thus in order for them to be used for this purpose in accordance with the law, they would have to be consigned to an entirely new category of technically dead, though physically alive, human beings.

As long ago as 1968 Madeleine Simms and Keith Hindell commented that 'by shifting the balance from

illegal to legal, medical termination of pregnancy will also cross the line from unethical to ethical, and from generally not done to generally acceptable' (7). In other words, what is generally done equals what should be done, and where legality paves the way, morality will inevitably follow. While ethically dubious in the extreme, this shift in attitude has certainly been demonstrated in the case of abortion, and would seem likely to be repeated in the case of anencephaly unless we can bring ourselves to view these babies as what they are – human beings with a profound disability, and unless we accept that the ultimate right of all living human beings is to their own lives, and not to someone else's organs. Length of life is quite irrelevant to this, and the law on homicide is definite on this point: 'The fact that it can be shown to have been virtually certain that the deceased would have died in any event, quite independently of the acts of the accused is irrelevant. Killing a man who is mortally ill . . . is just as much a homicide as it would have been to have killed him when he was in good health' (8).

If brain stem death is the criterion for other human beings to be accepted as organ donors, anencephalics are being regarded as exceptions to the rule only because they are weaker, which is clearly a political rather than a moral decision. Until their brain stem ceases to function they are no more dead than anyone else in this condition. They are genetically human children, and section 10:12 of the BMA's *Handbook on Medical Ethics* states that 'there are probably no circumstances in which a child can be considered a suitable donor of non-regenerative tissue. There is no legal certainty about a parent's right to give consent on behalf of the child, but if this exists that right cannot extend to any procedure which is not in the child's best interests'. I may not be a doctor, but even I know it is not in anyone's best interests to have their heart removed while they are still alive.

The same handbook also states in paragraph 10:30 that 'a decision by society that an individual either against his will or without being able to consent should have his life terminated is totally abhorrent to the medical profession'. In order for anencephalics to be used as donor banks we would have to overthrow this whole idea and replace it with one which allows us to dissect the living, if they are of greater usefulness to us in pieces than intact. I would expect (or rather perhaps hope is a better word in view of the current state of ethics in medicine) that this would not enjoy widespread appeal.

If human rights depend only on the size of our brains, or whether certain nerves and muscles work, we cross the line very definitely from individual worth to an inevitable and irrevocable linking between 'rights' and 'utility'. I think William Pitt the Younger was right when he said 'Necessity is the plea for every infringement of human freedom. It is the argument of tyrants. It is the creed of slaves'.

In my view the right to live one's life from conception to natural death is a universal and basic

freedom, not a commodity to be sold to the highest bidder or the strongest and most powerful. I believe that granting human rights selectively is indefensible and ultimately self-defeating and is indeed the moral equivalent of Milton's vision in *Samson Agonistes* – 'total eclipse without all hope of day'.

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### Editor's note

This paper stems from one given at a meeting of the London Medical Group.

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